

# Doing facial difference

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Valorization

# Doing more than research

Disseminating knowledge, developing  
clinical interventions

Parts of this chapter appear in a manuscript that is currently under review with an international, peer-reviewed journal.



By highlighting the lived experiences of individuals who have lost one or more parts of the face, this dissertation investigated the everyday impact of facial difference. This impact, as I showed in the previous chapters, takes shape mainly within the setting of everyday life. As they move through spaces, eat, practice hobbies, travel, use everyday objects, work, and interact with others, affected individuals experience various disruptions due to their physical dysfunctions and atypical appearance. It is also within this daily context that individuals who lack part(s) of the face actively relate to the disruptions associated with being amputated by developing new ways to inhabit their changed body and world. Adjusting to a radically altered face therefore involves more than physical and psychological healing: it requires the development of a new way of being-embodied-in-the-world.

As indicated in the discussion chapter, this perspective on facial limb absence can be of practical use for affected individuals themselves, as well as for the healthcare professionals working with them. This section briefly sketches out what shape this practical use may take. I start by reviewing the typical clinical trajectory patients go through. Next, I point out in what ways this trajectory is insufficiently oriented towards the lived experiences of individuals who have lost part(s) of the face, and why this is problematic. I then discuss several concrete measures to make these experiences count in the information, care, and support provided to patients throughout their treatment and its aftermath. In this way, I hope to pinpoint how this empirical-philosophical dissertation on patients' lived experiences may have value beyond the production of a PhD degree and academic publications.

The typical clinical trajectory is primarily oriented towards curative treatment rather than the everyday impact of treatment on patients' everyday life. As part of the process surrounding the decision to amputate, doctors and nurses typically inform patients about the expected outcome of the procedure (i.e. possible dysfunctions and facial 'disfigurement') and possibilities for prosthetic rehabilitation. After the surgery, when they recuperate in the hospital's ward, patients receive further information and support by the resident nurses. The focus here lies mainly on monitoring patients' healing, helping them establish self-care routines in treating the wound, and offering guidance as patients and their families first confront their altered appearance. In addition, nurses watch for signs of poor psychological coping, and may refer patients to mental health practitioners. After about two weeks, most patients are able to return home. A limited number of check-ups at the clinic then follow, after which the treatment comes to its conclusion. Once the amputated facial area has healed sufficiently, patients are also outfitted with a facial prosthesis at a prosthetics service unit (in the Netherlands and Belgium, these are most often affiliated with medical centers for cancer care). Because a typical device lasts for three to six months, most patients regularly return to the prosthetics unit for periodical adjustments.

This focus on curative treatment and postoperative healing within the clinical context means that the long-term adjustment of patients does not receive much attention.

Thus, patients are not informed about the practical, everyday challenges associated with physical dysfunctions and an altered appearance—including the ongoing work involved in managing these—before the amputation surgery. Likewise, the information, care, and support they receive while recuperating from the procedure are mostly geared towards their immediate recovery. And although nurses routinely monitor for poor psychological coping and body image disturbances, the protocols they follow focus only on the isolated individual's psychological difficulties. Consequently, problems emerging within the affected person's broader social context (most commonly due to the burden of managing unwanted attention) are not recognised or addressed. Moreover: physicians and nurses only incidentally refer patients to a mental health professional, and patients themselves rarely ask to see one. In addition, those who struggle emotionally after their return home remain undetected, and therefore do not receive a referral. Possible physical dysfunctions, too, are often not taken up in the clinic. Patients are not informed about the practical, everyday repercussions of these dysfunctions, nor do they receive professional support as they learn how to tackle everyday activities that are rendered more difficult by them. Indeed, individuals who have lost part(s) of the face seem to be somewhat of a 'forgotten group' within the clinic.

Of course, the fact this clinical trajectory is insufficiently oriented towards the context of everyday life cannot be attributed to ill-will or lack of professionalism of healthcare professionals. Rather, the extent to which the amputation impacts affected individuals' daily existence has until now simply remained uncharted. Because care practitioners do not have a sufficiently fleshed-out understanding of patients' lived experiences, they are unable to articulate how 'dysfunction', 'sensorial impairments', or 'disfigurement' translate into practical, everyday issues. Likewise, they remain unaware of the extent and nature of the continuous work involved in the management of these issues. As a result, practitioners are unable to convey the impact of the procedure to (prospective) patients, or address issues that may arise in its aftermath. Despite the efforts of the various professionals involved in their care, therefore, patients remain unprepared for the challenges they will confront after returning home, and do not receive enough support in managing these. As a result, individuals who have lost part(s) of the face are mostly on their own as they try to come to terms with their altered face after the amputation surgery.

The three empirical chapters of this dissertation demonstrate that these individuals all run into similar problems—and devise similar solutions—as they adapt to their amputation. Each in fact reinvents the wheel, as it were. Although the work involved in doing their facial difference remains significant, most find their way eventually. They nevertheless cannot learn from others' experience as they do so. As I mention in the discussion, many participants in my study were quite interested in others' experiences. This interest, I surmise, is due to the vacuum they find themselves in while adjusting to their altered body and world. Hearing about others' stories

offered respondents insight in and recognition of the various everyday challenges they themselves confront, and the work involved in managing these. Accounts that detail affected individuals' lived experiences, in other words, can provide an intimate and practical understanding of what it is like to live with a partly amputated face. Such an experience-based understanding could be of use to patients as well as healthcare professionals. Indeed, sufficient adequate in the lived experiences associated with the loss of part(s) of the face may help patients prepare for and handle the challenges they encounter upon their return home. It may also allow healthcare professionals to better inform, care for, and support these patients in different stages of their clinical trajectory and beyond. But how to ensure patients and care practitioners acquire an experience-based understanding of the day-to-day meaning of facial limb absence? I suggest there are three main paths towards achieving this end: (1) adjusting the clinical trajectory; (2); educating primary care practitioners; and (3) establishing close collaborations between medical centres, patients' organisations, and researchers. In the remainder of this chapter, I will briefly discuss each of these options.

Table 1: Publications for a lay audience

**Onderzoek: Leven met een afwijkend gezicht** (2018). HOOFD-HALS magazine, issue 9, February.

**Summaries of research findings** (2015-2016). Public website of the research project 'Bodily integrity in blemished bodies' ([www.mindthebody.eu](http://www.mindthebody.eu)).

**Tussen vreemdheid en eigenheid: werken aan een gaaf gelaat** (2012). In J. Jansen & T. Dobbelaar (eds). *Kijk anders. Zie meer. Tien jonge wetenschappers over disability studies* (pp 47-59). Rijswijk: Quantes.

**Leven met een ander gezicht** (2012). Nieuwsbrief van de Vereniging Oog in Oog, issue 49, volume 14.

Adjusting the clinical trajectory to ensure it is better attuned to the everyday impact of the loss of part(s) of the face can take place through two concrete measures. First, written handouts informing patients about their condition and its treatment prior to and after the amputation surgery could be adapted to discuss the meaning of the amputation in daily life. Specifically, patients should be offered clear descriptions of various practical issues they can expect to confront due to their physical dysfunctions and altered appearance. These descriptions would ideally avoid medical

jargon and normatively laden terms (e.g. 'defect', 'disfigurement'). In addition, it is important to discuss the ongoing work that is involved in the management of these issues. The topic of visible difference, in particular, should be addressed not only in terms of possible body image disturbances, but by highlighting the unwanted attention (stares, questions, comments) affected individuals stand to confront. To clarify how these issues take shape in affected individuals' daily context, it may be useful to offer concrete examples and even anonymized quotes. A list of secondary sources for further reference could also be included (e.g. websites of patient organizations, biographies of people who have various conditions that affect the face, accessible academic publications). In particular, patients could be directed to several texts presenting the

findings of this dissertation in an accessible manner to gain insight in the lived experiences associated with the amputation of part(s) of the face (see table 1 for an overview of these texts).

A second way to adjust the clinical trajectory requires more fundamental changes to its setup. These may include the revision of the aforementioned protocols currently used by nurses working in the head and neck ward. Changing the clinical trajectory may also involve the provision of standard-issue multidisciplinary rehabilitation and more elaborate aftercare. Thus, patients in the last phase of their hospital stay could routinely receive occupational therapy to help them adapt to possible physical dysfunctions. These patients could also receive customary referrals for social skills training in order to help them develop strategies for dealing with unwanted attention. In addition, patients' long-term adjustment could be monitored through regular follow-up appointments scheduled in the first two years after the amputation surgery. During these appointments, healthcare professions can explicitly address possible everyday challenges associated with the loss of part(s) of the face, and offer referrals to further rehabilitation or support. To reach patients who have undergone the procedure long ago, it may be helpful if the prostheticians affiliated with a particular clinic become more involved in the aftercare trajectory as a whole. Because they are the practitioners whom former patients see most often, prostheticians are in a unique position to identify those who experience long-term difficulties and refer them to further support. To do so, prostheticians would not necessarily require special training, but could simply use quantitative questionnaires to measure health-related quality of life or adjustment to 'disfigurement'.

Next to these proposed adjustments to the clinical trajectory, it is also important that healthcare professionals acquire a better understanding of the everyday impact of losing part(s) of the face. One way to foster such an understanding patients' experiences could be through presentations on affected individuals' experiences. In the last phase of my PhD trajectory, I have spoken about my findings for a number of different groups involved with these patients, including surgeons, nurses, prostheticians, rehabilitation practitioners and social workers (see table 2 for an overview of these talks). These groups were often surprisingly interested in the phenomenological approach to health and illness. Nurses, in particular, indicated that they should do more to better prepare and support their patients. Rehabilitation practitioners, too, were keen to find ways to ensure patients receive the aftercare they require. Indeed, such presentations not only inform healthcare professionals about the everyday impact of facial limb absence, but also persuade them that the information, care, and support they provide ought to become more attuned to this impact.

However, to ensure care practitioners become truly familiar with the lived experiences associated with facial limb absence, it would be best to develop more participative and practical forms of learning. Nurses, in particular, stand to benefit from further training in the daily challenges associated with sense-impairments, pain and other

uncomfortable sensations, and an altered appearance. Such additional training can take the form of workshops on the everyday impact of illness and disability, so-called ‘mirroring meetings’, or small-scale qualitative research projects. One way to make sure these sessions yield concrete outcomes, for instance, could be to ask nurses to improve the protocols they use in their work to reflect what they have learned about patients’ experiences. But rehabilitation practitioners and even physicians may benefit from such further training. These healthcare professionals could then use their newly-gained insights to the benefit of patients who have recently lost part(s) of the face—as well as that of other groups in the HNC ward who confront similar issues.

A final way to ensure patients and care practitioners gain access to lived experiences associated with facial limb absence would be through close collaborations between medical centres, patients’ organisations, and researchers. Thus, healthcare professionals could inform (prospective) patients about the existence of patient organizations for individuals with HNC, and facilitate meetings with so-called ‘patient informants’. Patient organizations, from their side, could do more to bring the everyday, practical challenges accompanying life with a different face into focus. These organisations often offer educational material on various types of facial difference, but could also include feature articles and testimonials on affected individuals’ lived experiences. Such stories would do much to ensure prospective and more seasoned patients gain access to others’ experiences—which they can hopefully relate to and learn from. Researchers could contribute to this effort by providing accessible texts on their findings to a

**Table 2: Presentations for healthcare professionals**

**Leven met een afwijkend gezicht: De geleefde ervaringen van individuen die een deel van het gezicht missen naar aanleiding van kanker in het aangezicht** (2018). Paper presented at the 232th Dutch congress for ENT specialists

**Leven met een zichtbaar veranderd uiterlijk naar aanleiding van de behandeling van hoofd-hals kanker** (2018). Presentation for medical social workers, Netherlands Cancer - Institute - Antoni van Leeuwenhoek

**De patiënt centraal? Ervaringen rondom een veranderd lichaam naar aanleiding van de behandeling van hoofd-hals kanker** (2018). Presentation for the head & neck rehabilitation team, Netherlands Cancer institute - Antoni van Leeuwenhoek

**Leven met een veranderd gelaat: Een kwalitatieve studie naar de ervaringen van patiënten bij wie een deel van het aangezicht is geamputeerd** (2018). Presentation for head & neck oncology nurses, Netherlands Cancer Institute - Antoni van Leeuwenhoek

**Een afwijkend gezicht doen: De ervaringen van individuen die een deel van het gezicht missen** (2017). Presentation for the working group ‘tumors of the head and neck’, Netherlands Cancer Institute - Antoni van Leeuwenhoek

**Living with facial difference: A qualitative study** (2017). Presentation for dentists, nurses and prostheticians, Center for Special Dentistry, University Medical Center Groningen

**Qualitative research into quality of life with a facial prosthesis** (2012). Paper presented at the symposium ‘Head-Neck Cancer in the Elderly Patient’, Netherlands Cancer Institute - Antoni van Leeuwenhoek



wider public (see also table 1), instead of focusing solely on academic publications. And clinics, patient organisations, and researchers together could lobby for a more patient-centred approach in the information, care, and support offered to individuals with facial limb absence.

Some of these measures can be easily implemented. Others require more time and effort. In my current position as postdoctoral fellow at the Netherlands Cancer institute - Antoni van Leeuwenhoek, I am now working together with various healthcare professionals to re-evaluate the information provided to (prospective) patients, and rewrite the complement used by nurses working in the head and neck ward. Embedding patients' experiences more fully within the head and neck (rehabilitation) rehabilitation trajectory, however, will require more fundamental measures. The next step is to develop a research project that explores implementation options—not only targeting those patients who have lost facial limbs and/or areas, but the entire HNC population.



